



# STATISTICS AND SOCIETY: A STUDY ON THE BURDEN EXPERIENCED BY CAREGIVERS OF PATIENTS WITH ALZHEIMER

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## ABSTRACT

The cost of caring for people with Alzheimer-type diseases is enormous. Caregivers experience emotional, physical and financial stress, and their demands are central to decisions on patient institutionalization. We hereby investigate the burden experienced by caregivers of Alzheimer patients in Cyprus. We explore whether burden is related to variables such as patient psychopathology, caregiver gender, income and level of education. Moreover, we examine if there is a significant difference in the level of burden, depression, or reaction to memory and behavior problems when patients live in the community or in institutions and if the level of burden is associated with the use of different coping strategies by caregivers. Various statistical techniques are implemented for the analysis and all the conclusions are discussed. This work was partially funded by the Cyprus Research Promotion Foundation.

## 1. INTRODUCTION

It is estimated that 10% of the older population is affected from Alzheimer-type diseases which result in cognitive impairment and memory loss and generally leave the affected person in need of supportive care. The growing interest on the subject has developed for two important reasons. The first reason is the increasing number of people expected to live over 80, where the incidence of the disease is almost 50%, accompanied by the enormous economic costs to the families and the society as a whole. The second reason is that most of the Alzheimer patients live at home, and it is estimated that over 75% of the home care is provided by the family. Many researchers concentrate on the care of people with Alzheimer's disease, labeling the caregivers of these patients as "the hidden victims" of the disease (e.g. Zarit et al., 1980). Caregivers are usually the spouses, who are the last to give up this role despite being frail themselves. They are usually left unaided, they are not trained to give nursing care, and they have no support from any professional or other group to give care at home.

The cost of caring is thus enormous. First, it is physical, since the caregivers, mostly the partners, are usually old, have their own health problems and have to deal with a very difficult and highly dependent patient. At the same time the cost is emotional, since caregivers lose the support, the companionship and the intimacy of their partner. Caregivers experience grief, which is similar to that of death or even worse, because the loss cannot be recognized openly or publicly and they are not socially supported as happens in real death. Finally, the cost is financial, because of the increased costs due to the illness and because of the low income due to retirement. The combination of loss, prolonged distress and biological vulnerabilities may compromise the physiological functioning of some caregivers, increase their risk of subsequent health problems and lead to the decision of institutionalizing the patient.

The purpose of this study is to investigate the burden experienced by caregivers of Alzheimer patients in Cyprus and the consequences of care on their mental health. The subject area in Cyprus is unexplored and there is a need to develop a database for other studies combining several methodological approaches. We explore how the pattern of vulnerability to the stressors of caregiving varies among the caregivers and whether burden is related to variables such as patient psychopathology, caregiver gender, income and level of education. Moreover, we examine if there is a significant difference in the level of burden, depression, or reaction to memory and behavior problems when patients live in the community or in institutions and if the level of burden is associated with the coping strategies used by caregivers. Various statistical techniques are implemented for the analysis and all the conclusions are discussed. The results of the study can be used to develop a theoretical basis for the development of family support programmes for Alzheimer patients and their caregivers.

## **2. RESEARCH METHODOLOGY**

### **2.1 Sample selection**

The sample size was targeted at 200 dyads (patient/caregiver). The exact number of people suffering from Alzheimer in Cyprus is not known, but it is estimated to be around 9,500. The criteria for inclusion into our sample were a) a diagnosis of Alzheimer disease made by a neurologist, b) the caregiver should be a relative who has most frequent contact with the patient and the greatest responsibility for care for at least one year and c) the caregiver should not be suffering from any psychiatric, mental or physical illness, so as to have the ability to undertake the care of a demented patient. This person was identified as the primary caregiver. Patients and their primary caregivers were recruited mainly from the Institute of Neurology and Genetics, which is the major health research center in Cyprus, from the Community Psychiatric services of the Government of Cyprus or they were referred from other neurologists and psychiatrists. Due to reasons such as difficult access to the specific population, medical doctors not being able to reveal the names of their patients and a recent law in Cyprus for protecting personal data, strict sampling methods (e.g. simple random sampling) could not be used. Therefore, when a list of 200 patients who satisfied the criteria was identified, the family was asked to indicate who the

primary caregiver was and then he/she was asked if he/she would volunteer to participate.

Out of the 200 dyads, the final sample size was 172 dyads; one patient died and 27 dyads refused to participate. The refusal of the 27 families although does not introduce a bias, is indicative of the social prejudice for the disease, which is considered as a stigma in this society. The caregivers were interviewed at their home, by the second author, and the data were collected during the period 2004-2005 (starting May 2004). The questionnaires were administered only to the caregivers, because the purpose of the study was to assess the patient's condition and the caregiver's feelings from the caregiver's perspective only.

## **2.2 Measuring Instruments**

The questionnaire consists of five parts. The first four parts are the main measuring instruments and the last part is on demographic data. The total number of variables is 158.

Part 1 assesses the patient's cognitive and behavior status, using the Memory and Behavior Problem Checklist (MBPC) (Zarit, 1990). There are two parts in the MBPC, each with 26 items. The first part determines the frequency with which common problems have occurred and the patient's cognitive and behavior status is scored on a Likert scale from 0 (never happens) to 4 (happens every day). The time frame used was one week and this period was selected to minimize the recall task for respondents. The second part measures the reaction of the caregiver. It obtains the subjective appraisal of each problem and measures the degree to which behaviors "bother or upset" the caregiver. It is on a scale from 0 (not at all) to 4 (extremely). Instrument validity was confirmed via comparison of the MBPC scores to other instruments. In the current study, reliability of the translated MBPC was measured using Cronbach's alpha, where high values close to 1 indicate high reliability, and gave  $\alpha=0.85$ .

Part 2 measures the level of burden of the caregiver. Burden is one of the most commonly used variables in caregiving research and it has emerged as a critically important public health issue. It is assessed using the Burden Interview (BI), which has been designed to assess the stress experienced by family caregivers of older people and disabled persons (Zarit et al., 1980) and has been widely used since then. BI consists of 22 questions scored on a Likert scale from 0 (never) to 4 (nearly always) about the impact of the patient's disabilities on the caregivers' life and how caregivers feel. The summated score on the 22 questions gives the overall index of Burden, where high values indicate high burden (highest score is 88). The BI was translated into Greek and back translated. The translation was evaluated regarding wording, grammar, content and cultural appropriateness for the Greek-speaking population and also submitted to a pilot group for feedback. This instrument has content validity, since it has been developed by researchers with clinical experience, working with Alzheimer patients and it reflects areas of common interest like health, economic situation, social life and personal relations. In bibliography it is suggested that the BI is used in order to provide a benchmark for comparison, since it is used by

most researchers. The reliability of the translated instrument was extremely high, with Cronbach's  $\alpha$  equal to 0.93.

Part 3 measures the presence of depressive symptoms and the level of depression of the caregiver, using the Center for Epidemiological studies-Depression scale (CES-D) (Raddloff, 1977). The CES-D is a 20-item scale used to assess the overall level of depression experienced in the past week, on a Likert scale from 0 (never) to 3 (most of the times), where the summated score on the 20 items is obtained. The reliability of the translated CES-D scale was at  $\alpha=0.69$ .

Part 4 assesses the strategies used by the caregivers to cope with the stressors of care, using the Ways of Coping Questionnaire (WCQ), which was translated and back translated and tested for reliability. Cronbach's alpha was 0.85. The Greek translation consists of 38 questions rated from 0 (never) to 3 (very often).

Exploratory Factor Analysis was performed on three of the instruments, in order to group the items in a few important factors. These factors will be the dimensions to concentrate on, in order to give specific measures and not only general advice for caregiving patients with Alzheimer. Principal Components with Varimax rotation was used, where the guidelines given in Hair et al. (1998), regarding the size of the factor loadings required for significance were followed. The 26 items of Memory and Behavior problems were grouped into 7 factors. These are inactivity, aggressive behavior, dangerous behavior, attachment to caregiver, memory problems, communication problems and depressive symptoms. Regarding burden, factor analysis gave 4 factors. These factors will be used as the dimensions of caregiver burden (summated scores of the items in each) and are: personal strain, role strain, relational deprivation and management of care. Personal strain includes items like caregiver feels weak, stressed, own health suffers, desperate, ready to collapse, hopes someone else could take care of patient. Role strain includes negative feelings of caregivers due to patient's behavior (feels angry, is afraid about the future, feels that patient asks for more help than he/she really needs), and also feels guilty about these feelings. Relational deprivation involves items that show caregiver's relations with family, friends and social network are affected, there is no time for themselves or their families, no social life, they cannot respond to all responsibilities at work. Management of care includes questions which evaluate the capability of the caregiver to provide help to the patient. A high score on this factor implies that patients do not get the necessary help and care and could suggest their institutionalization or assigning the care to someone else. Finally, the 38 items regarding the ways of coping with stress were grouped into 5 factors/strategies. These were: positive approach (positive reappraisal and problem-focused questions), seeking social support, wishful thinking or dreaming (wishes and seeking God's help), avoidance strategies (denial and resign) and assertiveness (assertive problem-solving approaches).

### 3. STATISTICAL ANALYSIS AND RESULTS

Some demographic results were obtained first. Regarding the patients, their mean age was 75.5 years, with standard deviation 7.93, minimum 52 and maximum 97 years. Out of the 172 patients, 130 lived at home (community) (mean age 74.5 years) and 42 lived in long-term institutions (mean age 79.8 years). Regarding the caregivers, there were 40 men and 132 women (77% were women). Their mean age was 56.8 years, with minimum 25, maximum 88 and standard deviation 13.38 years. The relation to patient was daughter (48.3%), spouse (41.3%), son (5.8%) and other (4.6%). About 32% were high-school graduates. 26.2% were government employees and 23.8% were housewives. Finally, most of the caregivers (60.5%) reported at least one health problem.

Results show that 68.02% of caregivers are highly burdened (i.e. have a burden score higher than 44, since the highest score is 88) and 65% of caregivers presented depressive symptomatology, which verifies that caregiving for Alzheimer patients is both stressful and burdensome. In fact, when depression is measured on the CES-D scale, 85 caregivers or 49.41% scored over 16 (cut-off point), which is considered as a risk level for the development of clinical depression (Yee and Schulz, 2000). Moreover, Pearson correlation coefficients for the main study variables show that burden is positively correlated with depression ( $r=0.57$ ,  $p\text{-value}<0.001$ ), the overall index for memory and behavior problems, MBPC, ( $r=0.54$ ,  $p\text{-value}<0.001$ ) and the reaction to these behavioral problems ( $r=0.63$ ,  $p\text{-value}<0.001$ ). Depression is also positively correlated with MBPC ( $r=0.35$ ,  $p\text{-value}<0.001$ ) and with the reaction to the behavioral problems ( $r=0.44$ ,  $p\text{-value}<0.001$ ). It is also positively related with three out of the four dimensions of burden, namely personal strain, role strain and relational deprivation ( $r=0.56$ ,  $0.51$  and  $0.47$  respectively, with all  $p\text{-values}$  smaller than  $0.001$ ). Finally, MBPC is positively correlated with the reaction to the patient's problems ( $r=0.89$ ,  $p\text{-value}<0.001$ ). If we consider the seven factors of MBPC separately (inactivity, aggressive behavior, dangerous behavior, attachment, memory problems, communication problems and depressive symptoms) we can see that each factor is positively related with burden; ( $r=0.37$ ,  $p\text{-value}<0.001$ ), ( $r=0.44$ ,  $p\text{-value}<0.001$ ), ( $r=0.36$ ,  $p\text{-value}<0.001$ ), ( $r=0.35$ ,  $p\text{-value}<0.001$ ), ( $r=0.22$ ,  $p\text{-value}=0.003$ ), ( $r=0.24$ ,  $p\text{-value}=0.002$ ) and ( $r=0.26$ ,  $p\text{-value}=0.001$ ), respectively. However, two of these factors are not significantly related with depression (memory problems ( $p\text{-value}=0.104$ ) and communication problems ( $p\text{-value}=0.064$ )). The other five factors have highly significant correlation coefficients with depression; ( $r=0.29$ ,  $p\text{-value}<0.001$ ), ( $r=0.26$ ,  $p\text{-value}=0.001$ ), ( $r=0.22$ ,  $p\text{-value}=0.004$ ), ( $r=0.24$ ,  $p\text{-value}=0.002$ ), and ( $r=0.19$ ,  $p\text{-value}=0.014$ ), respectively.

Next, we concentrate on the strategies that caregivers use to cope with the stressors of care. Burden is significantly correlated only with two of the strategies, positive coping strategies and wishful thinking: the correlation with positive coping strategies is significant and negative ( $r=-0.2$ ,  $p\text{-value}=0.01$ ). The correlation with wishful thinking is positive ( $r=0.16$ ,  $p\text{-value}=0.037$ ). Moreover, caregivers with low burden (score below the average) were examined to see if they use any strategy more than others. One-way ANOVA showed that there are indeed differences between the

strategies ( $F=22.71$ ,  $p\text{-value}<0.01$ ). Post-hoc Bonferroni multiple comparisons showed that strategy 5 (assertiveness) is used the least and strategy 1 (positive approach) is used the most, since they had the smallest (1.08) and largest (2.15) mean respectively and significant differences with the other strategies.

Results regarding the patient’s place of residence show that there is no significant difference in the levels of burden, Memory and Behavior Problems (MBPC), depression and coping strategies when the patient lives at home or in an institution. Table 1 gives summary statistics for the main study variables, when the patients live at home ( $n=130$ ) or in an institution ( $n=42$ ). Since the variables are formed as overall indices from the series of questions for each, they are approximately normally distributed and thus means and standard deviations are reported. In the same table we also have the results from the independent samples t-tests, to identify any significant differences regarding these variables between the community and institutions participants. The p-values for all the variables are very high, indicating that there are no significant differences between the two groups.

**Table 1.** Patient’s place of residence and Main study variables

Variable	Place of residence	Mean	SD	t	p-value
Burden	home	50.29	17.35	1.55	0.12
	Institution	45.60	16.13		
MBPC	home	48.80	20.66	-1.29	0.20
	institution	53.33	16.54		
Depression	home	18.68	7.27	-0.28	0.78
	institution	19.05	7.04		
Reaction	home	47.65	21.42	-0.33	0.74
	Institution	48.69	16.22		

Therefore, results show that there are no statistically significant differences in caregiver burden, when the patient is placed in a long-term care setting compared to living in the community ( $p\text{-value}=0.12$ ). However, when burden is represented by its four factors some differences do exist. There is a difference in relational deprivation, which seems to be higher when the patient lives at home ( $M=10.40$  for community and  $M=8.69$  for institution,  $p\text{-value}=0.03$ ). It is also interesting that when the patient lives in a long-term institution, factor 4, management of care, is higher (community  $M=2.66$ , institution  $M=3.54$ ,  $p\text{-value}<0.001$ ).

The examination of burden in relation to caregiver education and income, demonstrated that there are differences. Regarding caregiver education, the F-statistic from one-way ANOVA was 3.69 with  $p\text{-value}<0.01$ . Post-hoc multiple comparisons (Bonferroni) reveal that a significant difference in burden exists between caregivers with the lowest and highest level of education, where elementary school graduates have higher burden compared to MSc/Phd holders ( $p\text{-value}=0.046$ ). Regarding income, the F-statistic is 3.2 with  $p\text{-value} 0.02$ . We have four income levels, namely “no income”, “up to 6000 Cyprus Pounds (CYP) per year”, “between 6000 and 12000

CYP per year” and “over 12000 CYP per year” (1CYP=1.71Euro). Multiple comparisons show that a significant difference exists between those in level up to £6000 and those over £12000 per year (p-value=0.03), where the first group (i.e. with the lower income) has a higher burden. A marginal difference exists between the no-income group and the group with income over £12000 per year (p-value=0.087).

Gender differences were also examined. From an independent samples t-test it was observed that depression and burden are different among men and women (p-values 0.011 and 0.048 respectively). More specifically, women have a higher burden score and higher depression levels than men. If we also examine the individual factors of burden and their relation to gender, we can see that factor 3, relational deprivation, is the only one that significantly affects gender differently (p-value=0.02), women more than men, and personal strain also has marginal difference. All the results regarding gender differences in burden and depression appear in Table 2.

**Table 2.** Gender differences in caregiver burden and depression

Variable	Gender	Mean	SD	p-value
Depression	men	16.25	5.75	0.011
	women	19.54	7.43	
Burden	men	44.45	18.89	0.048
	women	50.57	16.38	
Factor1: personal strain	men	20.57	9.65	0.090
	women	23.45	7.70	
Factor 2: role strain	men	12.75	6.03	0.360
	women	13.73	5.90	
Factor 3: relational deprivation	men	8.47	4.52	0.020
	women	10.44	4.50	
Factor 4: management of care	men	2.65	1.29	0.250
	women	2.95	1.77	

Finally, gender differences are also observed in the coping strategies used by caregivers, where the results showed that women use “seeking social support” more than men do (p-value<0.01, mean for women=1.98, mean for men=1.66, with standard deviations 0.65 and 0.67 respectively). Similarly women use “wishful thinking” more than men (p-value=0.03, mean for women=1.92, mean for men=1.66 with standard deviations 0.65 and 0.67 respectively). Avoidance strategies are also marginally used more by women compared to men (p-value=0.09).

#### 4. DISCUSSION

This study has shown that the majority of family caregivers experience high levels of burden and score over the risk level for the development of clinical depression. This finding can be explained by the long duration of caregiving career which ranges from 1 to 13 years and the tensions involved in this role that possibly lead to

psychological and physical health problems. Results have also shown that the important variables are positively correlated. That is, the more the psychopathology of the patient (measured by MBPC), the higher the level of burden and depression and the more intense the reaction of the caregiver. The relation between memory problems (e.g. asks the same question over and over again, mixes up past and present, loses things, misplaces or hides things) and depression of the caregiver is very weak. It seems that behavioral problems have far greater impact on the caregiver than do cognitive or functional impairment and this could give a direction for symptom management approaches.

Most of the caregivers are women spouses or daughters at their 50's, which shows that women are more likely to become caregivers in their course of life and that caregiving has traditionally been viewed as the responsibility of women. Results show that women in relation to men have higher burden and depression scores. As elsewhere, in the Cyprus society cultural norm the caring role belongs to women and many women have undertaken this role not by choice, but because it is socially imposed on them. It is expected from women to fulfill the difficult task of care without preparation or knowledge, just because it is an important characteristic of their female nature. The traditional view that caregiving is an obligation and family responsibility, creates to women increased feelings of tension and sadness. Men and women do not experience burden in the same way. Women caregivers are suffering from social or relational deprivation, which in other studies is reported as "isolation factor" or "restriction in social life". However, beyond the role differences there is a possibility that certain male personality characteristics may function as strong factors promoting resistance to stress. It may also be possible that men have developed a stronger and wider repertoire for the management of stress because of the many years of work and the more positive approach of difficulties. Men caregivers also seem to use such mechanisms that create a psychological distance from the patient so as to reduce the stress of care and they often receive informal help, which lowers their levels of burden.

Gender differences have also been reported regarding the ways people use to cope with the several stressors of caregiving. Women seem to have lower levels of mastery and use less effective coping strategies, while men use mostly problem solving approaches. Women in this study reported that they use emotional, avoidance and escape coping strategies more than men, explaining to a degree their high levels of burden and depression.

As evidenced by the results of the study, even though burden is related with the psychopathology of the patients, caregiver depression and burden are the same for caregivers who provide institutionalized care with the caregivers who care for at home. These results probably mean that the caregivers suffer from feelings of guilt associated with the social stigma that accompanies neglect and institutional placement. Another explanation may be that caregivers continue to be involved in their relative's care and they face additional practical problems of transportation, relationships with the staff of the institution, or they are equally burdened simply



because their relative goes into the final stages of the disease and they are forgotten by the society and thus experiencing overwhelming sadness and depression. Moreover, the patients who live in an institution have the same frequency of problems with the patients who stay at home and also the reaction of the caregiver to the patient's problems is similar in both cases. This means that problematic behavior does not contribute to the decision for institutional placement. In other words, it appears that institutionalization does not seem to be the answer to the problem of burden.

A relationship exists between the caregiver burden and the profile of the caregiver, in terms of the level of education and income. It was found that caregivers with higher education and better remuneration have lower levels of burden. It seems that these factors may function as buffers to the stressors of caregiving. It is also possible that these caregivers have developed more effective skills in managing the problems of care and their own stress.

The overall conclusion is that the role of caregiving and the "new career" caregivers are enforced to follow, places them in an extremely vulnerable situation. The coping strategies used are not enough to relieve caregivers and restricts the potential to offer a high quality of care to the sufferer. The findings have great implications for intervention programs and contribute to the prevention of unnecessary morbidity of caregivers, the prevention of patient premature institutionalization and promotion of health for both the caregiver and the care recipient. With recognition that the mental health and well being of caregivers are important factors in the care of Alzheimer patients, numerous efforts need to be taken to develop and expand support services and programs for them. In a time of increased limitation of resources and funding, the principle of efficient training of those caregivers in most immediate need and the effective and timely identification of the core problem issues are growing in importance. Caregivers, especially females, need to receive individualized, specific training on how to understand and manage the behavior of Alzheimer patients and how to cope with their own feelings.

## **ΠΕΡΙΛΗΨΗ**

Το κόστος για τη φροντίδα ασθενών με άνοιες τύπου Αλτσχάιμερ είναι τεράστιο. Οι φροντιστές αντιμετωπίζουν συναισθηματικά, σωματικά και οικονομικά προβλήματα, και οι ανάγκες τους είναι σημαντικές για αποφάσεις σχετικές με την ιδρυματοποίηση των ασθενών. Στην παρούσα εργασία εξετάζουμε την επιβάρυνση φροντιστών ασθενών με Αλτσχάιμερ στην Κύπρο. Διερευνούμε αν η επιβάρυνση σχετίζεται με μεταβλητές όπως η ψυχοπαθολογία του ασθενούς ή το φύλο, το εισόδημα και το επίπεδο μόρφωσης του φροντιστή. Επίσης, εξετάζουμε αν υπάρχει στατιστικά σημαντική διαφορά στα επίπεδα επιβάρυνσης, κατάθλιψης και αντίδρασης στα προβλήματα μνήμης και συμπεριφοράς του ασθενούς, όταν οι ασθενείς ζουν στην κοινότητα ή σε ιδρύματα και αν η επιβάρυνση σχετίζεται με τις στρατηγικές αντιμετώπισης που χρησιμοποιούν οι φροντιστές. Διάφορες στατιστικές μέθοδοι χρησιμοποιούνται για την ανάλυση και διεξάγονται ενδιαφέροντα συμπεράσματα. Μέρος αυτής της μελέτης χρηματοδοτήθηκε από το Ίδρυμα Προώθησης Έρευνας.

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